

THROUGH THE LENS OF THE ASD SELF-ADVOCATE

2015 AUTISM CONFERENCE: BUILDING
BRIDGES THROUGH SELF-ADVOCACY
ACROSS LIFESPAN

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Goals of the Presentation

- 1. Learn factors that help promote self-advocacy.
- 2. Learn personal qualities that promote self-advocacy.
- 3. Learn ways families can facilitate self-advocacy skills in themselves and their children.
- 4. Identify your personal areas of growth to enhance personal self-advocacy.
- 5. Identify key resources and organizations available to assist families in self-advocating.

What are Developmental Disabilities ?

- A severe, chronic disability
- Attributable to a mental or physical disability or a combination of mental and physical disabilities
- Is manifested before the person is (18) 22 years of age
- Is likely to be life-long.
- Results in substantial functional limitation in 3 or more areas of major life activity

(Kleinert, H., presentation, 9-02)



Developmental Disabilities May Result In Deficits in...

- Self-Care,
- R/E Language,
- Learning,
- Mobility,
- Capacity for Independent Living,
- Economic Self-sufficiency,
- Self-Direction OR Self-Determination.
- (Kleinert, 9-02)



The road to advocacy...

- Self-determination sets the stage for disclosure, which makes self advocacy possible.
- Self- determination
 - ▢ Make the individual aware of their strengths and challenges through verbal, pictorial, and other methods
 - ▢ Nonjudgementally compare list with positive role models
- Develop an understanding of ASD
- Help individual learn ways to get their needs met in ways others can understand and respond positively.

Ways to promote self-advocacy

- Provide teachers and service providers of students with developmental disabilities training in use of the Self-Determined Learning Model of Instruction (SDLMI, Agran, Blanchard, & Wehmeyer, 2000).
- The Self-Determined Learning Model of Instruction is a self-regulated problem-solving format used with individuals of any age to:
 - ▢ 1.) Set a goal
 - ▢ 2.) Develop a plan and
 - ▢ 3.) Evaluate a plan or goal.
 - ▢ It is a discussion process used by a teacher/services provider to support a person to express interests, prioritize needs, and accomplish something in a specific situation or environment.

Ways to promote self-advocacy

- Provide mentors in self-advocacy, who themselves have a disability, to children with developmental disabilities.

Ways to promote self-advocacy

- Demonstrate that children/youth with significant disabilities and students who have or need augmentative communication can be successful self-advocates.

Ways to promote self-advocacy

- Provide children with disabilities a venue to share their accomplishments in self-advocacy.
- Participation in Bucks County My Story

Ways to promote self-advocacy

- Develop and disseminate materials for use by teachers, children, families, and service providers.

Why Teach Children/Youth with Disabilities Self-Advocacy Skills?

Research has shown that:

- individuals with disabilities who have strong self-determination/self-advocacy skills and those who utilize augmentative communication systems to express themselves have better post-school outcomes and reported quality of life (Hamm & Nirenda, 2006; Wehmeyer & Garner, 2003; Wehmeyer & Schwartz, 1998).
- young students, including those with autism, have been found to increase their participation in academic work and decrease negative behaviors when given opportunities for choice in the academic setting (Jolivet, Stichter, & McCormick, 2002; Moes, 1998).
- children, as young as kindergarten age, have been shown to successfully utilize a self-determined learning model of instruction with teacher assistance (Palmer & Wehmeyer, 2003).

By beginning training in self-advocacy and self-determination at a young age, we give children with disabilities a head start on an improved quality of life, improved post-school outcomes, and increased participation in current academic programs

What is Self-Determination?

- The ability to control the basic decisions and directions of one's life
- *"The freedom to have choices and personally make decisions is cherished by people in all stages of life, yet it is a freedom that is typically denied to persons with disabilities."*
(Falvey, 1995, p. 229)

The Focus of Self-Determination

The focus of self-determination is on a person's ability to make choices about his/her life, to select goals, and to develop the initiative to go after these goals.

Self-Determination...

- is especially important for students and youth with significant disabilities because for most of these individuals, their choices have not been made by themselves, but by parents, guardians, teachers, and service providers.
- is not just a matter of lack of opportunity.

(Kleinert & Kearns, 2001)

Unfortunately

- Many students with significant disabilities do not have the skills and behaviors to assume that control over their lives and few educators and service providers know how to teach the components of self-determination.

(Kleinert & Kearns, 2001)

What Fosters Self-Determination?

THE ABILITY TO
COMMUNICATE
CLEARLY Helps to
Foster DEVELOPMENT
OF A **SELF-**
DETERMINED LIFE

(Light, 2000; Kleinert, 2007)

Skills of Self-Determination

- Choice-making
- Self-initiation
- Self-monitoring
- Self-reinforcement
- Goal setting
- Asking questions
- Planning one's own schedule
- Self-regulation
- Persistence
- Self-awareness

(Agran et al., 2003; Kleinert et al., 2001; Wehmeyer, 1998)



How Can We Support Self-Determination ?

- Opportunities for choice
- Functional activities
- Experiencing success
- **Self-advocacy**
- Making decisions re: their schedules at school, at home, work, leisure, in therapies, etc..

(Proponents include: Wehmeyer, Brown, Field, Falvey, Kleinert and others)

Skills that contribute to successful outcomes for persons with disabilities include:

- **Strong communication skills**
- +
- **Self-determination**

May result in Self-Advocacy

Educators, Therapists, School Personnel Often Focus on...

Social and Language Skills such as:

- requesting
- refusing
- indicating preferences
- Initiating

Executive Functions such as:

- Goal Setting,
- Planning,
- Self-Monitoring,
- Problem Solving

Self-Advocacy

- **IMPORTANT AT ALL AGES**
- Begins with the ability to make choices
- Express preferences and dislikes
- Realistically identify our own strengths and needs
- Identify Barriers
- Problem solve
- Self-evaluate our progress
- Revise our plans

Adaptations

Adaptations can be developed for students who have difficulty:

- Expressing themselves
- Indicating preferences and dislikes
- Making Choices
- Self-monitoring
- Problem solving

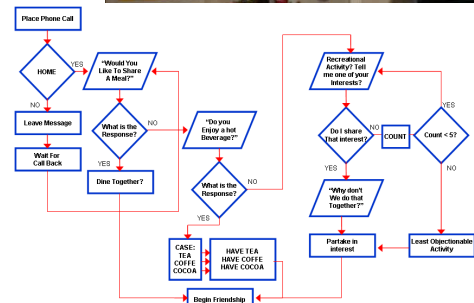
Social Skills Training

- Speech services
- Occupational services
- Scripting
- Rehearsal
- Confederates
- Social Stories
- Shadowing

Parenthood, BSC: Shadowing



Social observations:

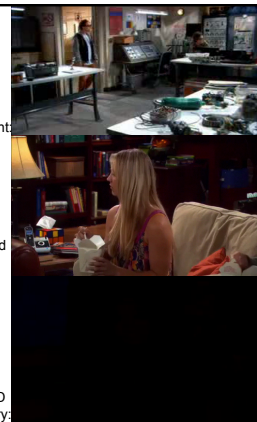


- Introduction w/reason for approach
- "Safe" compliment
- Repeat x 3:
 - Question @ what they might like
 - Wait for response
 - Self-disclosure
- Wait for lack of response
- See-you-later w/reason for ending
- Additional interventions:
 - Videotape
 - Mentoring
 - Real-life Confederates
 - Eye contact, nod, and facial recognition/memory



- Stephen Shore's "sleepover"
- Temple Grandin's asexuality?
 - "I have been reasonably happy even though I am totally celibate...My lifestyle is not for everyone with Asperger's. It was easier for me because the brain circuits that made my friend Carol swoon over the Beatles are just not hooked up in me."
- Pitfalls and dangers

Loving Lampposts, Stephen Shore: BBT, Kiss Experiment
[REDACTED] BBT, Child bearing:
[REDACTED] ABC, ASD Love Story



Finding your niche, being yourself

Here are some tips from 15 y/o Haley Moss, autistic:



1. **Seek help if you don't understand something:** People with autism spectrum disorders are often detail-oriented and miss the bigger picture, Haley said. Her mother would read English books with her and discuss the themes to help Haley see them more clearly. Haley recommends consulting parents, siblings, teachers and textbooks if you are stuck on something.
2. **Learn about trends to talk about them:** Haley's approach to popular culture is methodical and detached: learn about the trends to fit in, even if you don't like them. She saw all the "Twilight" movies on opening night even though she doesn't like the franchise much. She can recognize a popular Jonas Brothers song. Being up on the fads helps with socializing and avoiding ridicule, she said." In middle school, everyone just cares that you're like them, and if you're different, you get picked on," Haley said. "No one accepts different people."
3. **Trust your parents:** People with autism spectrum disorders tend to assume that everyone is trustworthy, and that can make them be easily manipulated, Haley writes. She recommends having a good relationship with your parents and entrusting them with your secrets instead of someone at school. Her parents help her with academic and social problems. Also, she looks to her mother to interpret classmates' comments that she didn't understand, instead of jumping to conclusions.

Hyper-focus as a strength

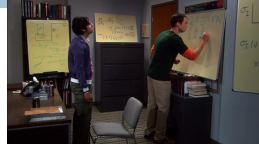
Parenthood: Bug birthday



BBT: patience with ring

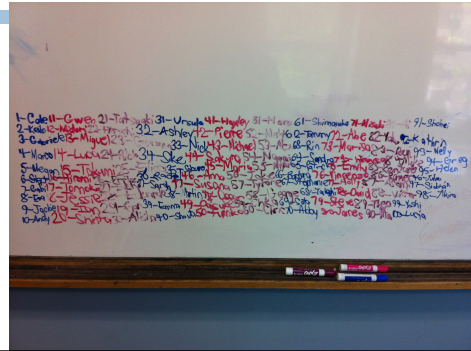


BBT: working on equation, Rocky



Hyper-focus as a strength

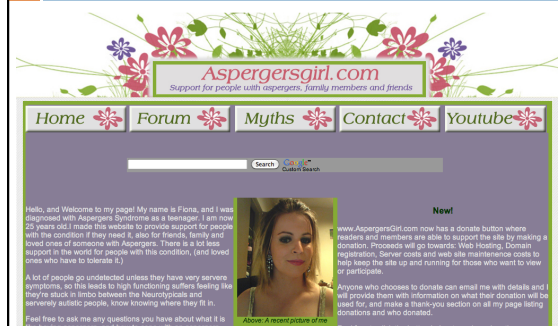
Vast detail retrieved by client:



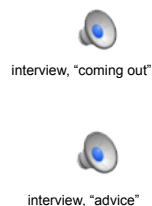
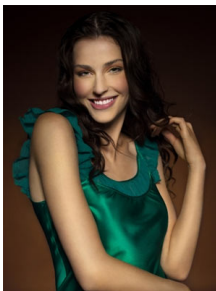
Egocentrism as a Strength?



YouTube: AspergersGirl... Connecting around the world



Heather Kuzmich America's Next Top Model



interview, "coming out"


interview, "advice"

Temple Grandin HBO Movie



- Saturday, February 6, 2010, 8pm, HBO
- Viewing parties around the country
- Families watching together
- Inspiration and reframing ASD for families
- Role-model for Autistics... Client: "I want to work with animals too"

17 Wishes from an Adult with Autism, by Kerry Magro



1. I wish that acceptance was easier to come by
2. I wish that loving one another was always on our mind
3. I wish that an "early diagnosis" remains a high priority
4. I wish that people would stop calling autism a disease
5. I wish that communication becomes easier for everyone with autism. We are trying.
6. I wish that we find more treatments to enhance the lives of people with autism
7. I wish that insurance for autism gets passed in all 50 states
8. I wish that the government would understand the need for services for the autistic in schools
9. I wish that autistic individuals can one day live their lives independently
10. I wish that I was capable of helping more
11. I wish that people would stop using the words "socially awkward" and "retard" in a negative way
12. I wish we raise awareness for all with disabilities. Those of us living with a disability are doing our very best.
13. I wish for those who are or love someone who is on the spectrum that you know that we are moving forward every single day.
14. I wish that all of our voices can be heard.
15. I wish everyone will follow the words of one of my favorite performers of all time, Michael Jackson who sang in his song called, "Man in the Mirror", *If you want to make the world a better place, take a look at yourself and make a change.*
16. I wish you all knew me when I was 4, when I was diagnosed with autism. For a long time I was lost. Scared of myself and what I was capable of. I never thought I would be where I am today... but I did it. I graduated from Seton Hall University this past May and will be going to Graduate School for Strategic Communications in the fall to boot. So for my final wish:
17. I wish for you all to always live life with hope. I wish that your days are filled with hope for a better tomorrow, and for today no matter how dark life gets sometimes that you realize you're never alone. I wish this for you.

Humor

Soil

by Dan Woodman

1-2-punch.... NT


Repetition... ASD

Types of humor

- irony
- difference in expectations, incongruity
- plays on words
- absurd ideas
- loopholes in rules or expectations

Examples:


- "get outta here"
- "macaroni salad"



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Matt Friedman

www.dudeinmanaspie.com




My name is Matt and I have Asperger's syndrome. What's that mean, you ask? Well, you're in luck, cause I've made this helpful guide!

Asperger's is part of the autism spectrum. It has many characteristics, but generally we have difficulty knowing what someone is thinking, explaining our thoughts verbally, and interacting socially with our peers. It is sometimes described as having "a dash of autism."

Photography from the eye of ASD

German Photographer



Use mouse to advance slides

Self-Advocacy

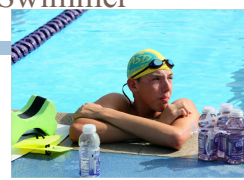


Alexis Wineman, 2012 Miss Montana

Kendall Bailey, ASD Swimmer

As a child...

- Uncomfortable all the time...
- except when in water
- Water was calming
- Craved the feeling of being enveloped
- When hysterical:
 - lay in empty backyard kiddie pool
 - parents poured gallons of rice over him
- Coach: "I think swimming always suited him because he doesn't interact with people in the water — he can isolate himself in his own little world, and the flow of the water around his arms and legs, it just feels good to him — and the faster he goes, the better it feels."
- Mother: \$25,000 in legal fees to get U.S. Paralympic Committee to drop eligibility appeal: "It could take him under for life, I mean it could make him a whole different person.... He's been singled out and isolated because of his autism, because of his intellectual disability. If Kendall wasn't autistic, would any of this have happened? Absolutely not."



Neurodiversity

Amanda Baggs



- Self-advocacy via internet
- Higher level of interaction with entire environment
- People may be seen as objects, but not necessarily less important as entire environment becomes important
- Blogging and social networking
- Second-life

Carly Fleischmann

- "Technology has allowed me to communicate, learn social skills, implement relaxing techniques and played a crucial part in helping me how to spell. To me, technology is the key to unlocking autism."
- Facebook, Twitter and blogging

Amanda Baggs, self-advocat

Carly on panel about technology and autism with






Neurodiversity

Meaghan Flemming Buck

Jon Dorfman

- ASD at Community College of Philadelphia rose from 3 to 25 from 2007-2011
- "Colleges are seeing more people with autism spectrum disorders, the kinds of people who, in the past, wouldn't have gone on to college," says Felicia Hurewitz, director of the Autism Support Program at Drexel University. "We have a lot of diversity. Neurodiversity is the newest."
- Accommodations: copies of lecture notes, extended time, quiet testing area, tech supports, peer mentoring, single rooms, group supports, open mics, academic/organization support
- AHEAD (Achieving in Higher Education with Autism/Developmental Disabilities)

Autism Expressed

Michele McKeone, South Philadelphia High School AS teacher

- Teaching students digital media and life skills
- Developed online curriculum: <http://www.autismexpressed.com>





"Digital media has helped me to express myself. My favorite application is Blogger because I like to create my own personal blogs!"

DeShaun Cole, Student with Autism

Let's Get Functional

- Fixations as wonderful strengths
- The right niche
- Identify functional fixations early
- Preparing fixations for vocational and post-secondary opportunities
- Promoting housing that complements the fixations
- Assessment, FISH, etc., and the role of intuition
- Job carving
- Workplace consultation
- Follow through
- Allies

Temple Grandin:



Using Fixations to Develop Skills


- May 2013: autistic/Tourette's 18-year-old Cory Singer, finalist, Bravo TV's talent competition, "The Kandi Factory"
- The stage is his best medicine, "because I get to become someone else."
- He learned full choreography and recorded a track written just for him.
- track released via iTunes and a video to accompany it
- Mother: He "focuses on his abilities, not his disabilities."
- Preparing to audition for the Boston Conservatory

Robots helping with social skills

Autism Spectrum Disorder



Walgreens... a new model



Other companies carving out spots for Autistic Employees

- Genuardi's
- Freddie Mac, a leading mortgage lending company, is partnering with the Autistic Self Advocacy Network to place Autistic interns in full time, paid positions. Freddie Mac is dedicated to include Autistic people as part of a diverse workforce. All positions will be held on the Freddie Mac campus in McLean, Va. Accepting the job requires relocation for people outside the Washington, D.C. metro and surrounding areas. Resumes will be accepted through June 14, 2013. Each internship will last for 16 weeks from the start date. Internships will start in early July 2013. Resumes must be sent to resumes@autisticadvocacy.org.

The Specialists

- <http://www.abcnews.com/2013/06/11/specialisterner-abc-news/>
<http://news.abc.com/2013/06/11/specialisterner-abc-news/>
<http://www.abcnews.com/2013/06/11/specialisterner-abc-news/>
<http://www.abcnews.com/2013/06/11/specialisterner-abc-news/>
- Specialisterner: Software Testing in Denmark
 - 60 consultants are considered best-in-class
 - paid industry-competitive wages
 - customers include LEGO, Microsoft, and Oracle
 - 75 percent have Asperger syndrome or some form of ASD
 - consultants enjoy their work and are great at it
 - Testing process—checking and rechecking outcomes, documenting test plans, and maintaining follow-through
 - making use of high intelligence, precision-oriented skills, deep concentration, and patience that can be positive features sometimes accompanying ASD
 - "This is not cheap labor, and it's not occupational therapy... We simply do a better job."
 - Model is taking off with public and private funding
- ABC News: Specialisterner

RESOURCES

Efficacy of Efforts to Promote Student Involvement

- Data exists to support the efficacy of the following interventions/programs:
 - Next S.T.E.P. (Halpern, et al., 1997)
 - Published by ProEd (<http://www.proedinc.com>)
 - Self-Directed IEP (Martin, Huber Marshall, Maxon, & Jerman, 1997)
 - Published by Sopris West (<http://www.sopriswest.com/>)
 - Information on Zarrow Center at OU website (<http://education.ou.edu/zarrow/>).

Efficacy of Efforts to Promote Student Involvement (cont.)

- Data exists to support the efficacy of the following interventions/programs:
 - Self-Advocacy Strategy (VanReusen et al., 2002).
 - Contact University of Kansas Center for Research on Learning (<http://www.ku-crl.org/>).
 - Whose Future is it Anyway? (Wehmeyer et al., 2005).
 - Available online at OU Zarrow Center (<http://education.ou.edu/zarrow/>).

Measuring Self-Determination

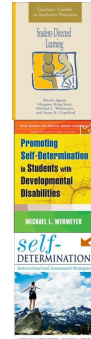
- The Arc's Self-Determination Scale (Wehmeyer et al)
 - Self-report measure of self-determination for students with cognitive disabilities.
- AIR Self-Determination Assessment (Mithaug et al)
 - Student, teacher, and parent report versions
- ChoiceMaker Self-Determination Assessment (Martin et al)
 - Curriculum referenced measure.
- Wayne State University Self-Determination Assessment Battery (Field et al.)
 - Student, parent, teacher versions, observation checklist
- All available online at OU Zarrow Center web site (<http://education.ou.edu/zarrow/>).

Resources: Websites

- UNCC Self-Determination/Self-Advocacy Synthesis Project site
 - <http://www.uncc.edu/SDSP/>
- OU Zarrow Center website
 - <http://education.ou.edu/zarrow/>
- KU Beach Center on Disability website
 - <http://www.beachcenter.org/>
- Allies in Self-Advocacy
 - <http://alliesinselfadvocacy.org/resources/>

Resources: Books

- Teaching Student-Directed Learning (Agran et al. 2003), Paul H. Brookes (<http://www.pbrookes.com>)
- Promoting Self-Determination in Students with Developmental Disabilities (Wehmeyer et al., 2007), Guilford Press (<http://www.guilford.com/>)
- Self-Determination Instructional and Assessment Strategies (Wehmeyer & Field, 2007), Corwin Press (<http://www.corwinpress.com/>)



If you've met one
person with autism,
you've met one
person with autism

Stephen Shore (and others)